Guide to Chapter 4

CHAPTER 4

Options for Designing Service Coverage: General Considerations[1]

To remain in their homes and communities, many people with disabilities and chronic conditions need long-term services and supports that can range from personal assistance to more specialized services. Federal Medicaid law and policy give states great latitude to offer individuals a wide range of home and community services through the state's "regular" Medicaid program. States can offer an even more comprehensive service range by operating one or several home and community based services (HCBS) waiver programs. This chapter explores Medicaid coverage options, including important issues states need to consider in selecting the particular combination of home and community services and benefits that best suits their respective needs.

Introduction

Twenty-five years ago, the Medicaid program offered few avenues for securing Federal dollars to support people with chronic illnesses and disabilities in home and community settings. Except for limited home health services, Federal Medicaid funding for long-term care was available only when persons were placed in an institutional setting (e.g., a nursing facility, an ICF/MR, or a medical rehabilitation or mental health facility). Changes in Federal Medicaid policy over the years now make it feasible for states to provide home and community services to individuals who need long-term services. As a result, states have considerably expanded availability of home and community services. Indeed, the fact that Medicaid offers so many options for furnishing such services can be confusing for policymakers, state officials, advocates, and consumers alike.

The wide range of home and community service options available to states comes through one or both of two alternative Medicaid funding routes: (1) a state's "regular" Medicaid program and/or (2) one or several HCBS waiver programs, each offering a distinct package of services and supports to different groups of individuals. Combining these alternatives in creative ways gives states substantial latitude in designing their Medicaid home and community service coverages and customizing benefit packages to meet the needs of particular groups. Using waivers in this manner also gives states considerable flexibility to manage the cost of services and the rate of growth in the number of people served. Because of this flexibility, states vary considerably in the services and supports they offer.

This chapter begins with an overview of the broad types of Medicaid home and community services and supports a state may offer. It then describes major Federal and state considerations that influence decisions concerning whether to offer a service as a regular Medicaid program benefit or via an HCBS waiv-

er program. The chapter concludes with more detailed descriptions and illustrations of coverage options—focusing first on services that may be offered under the regular Medicaid state plan and then on services that may be offered under an HCBS waiver program.

Medicaid Home and Community Services: An Overview

Home and community services can be thought of as falling into five overarching categories. It is useful to consider these in generic terms before proceeding to a detailed discussion of how they are treated in Medicaid law and policy.

Personal Care and Assistance. Personal care and assistance involves helping individuals perform everyday activities when they have a physical or mental impairment that prevents them from carrying out those activities independently. These activities can include Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include eating, bathing, dressing, toileting, transferring from bed to chair, and maintaining continence. IADLs include activities such as light housework, laundry, transportation, and money management. (ADLs and IADLs are discussed in more detail in Chapter 3.)

Providing personal care and assistance can take the form of a paid worker (e.g., a personal care attendant or a home health aide) helping the individual each day in the home or elsewhere in the community. This assistance is also furnished to individuals in other community living arrangements, such as group homes and assisted living facilities.

Individuals with various types of disabilities often require this form of basic assistance throughout their lives. Hence, it is a major, if not the primary, reason many individuals seek Medicaid long-term care services. States use several different terms to describe assistance with ADLs and IADLs, which may be provided as part of the home health benefit, as a personal care option under the state Medicaid plan, or through a waiver program.

Health-Related Services. Long-term health and health-related services include a wide range of skilled and unskilled nursing services to address chronic conditions (e.g., tube feedings, catheterization, range of motion exercises).

These services are covered under Medicaid's home health benefit, but can also be covered under a waiver program. The major source of primary and acute health care benefits for persons with disabilities is the basic Medicaid state plan. States also have the option to offer additional health care services to supplement these benefits through an HCBS waiver program. These services may be provided under a state's personal care benefit through the state plan when they are delegated by a nurse and when the practice is recognized and permitted under state law. (Nurse delegation is discussed in detail in Chapter 7.)

Specialty Services. Specialty services encompass an enormous range of services related to the specific nature of an individual's impairment. By and large, these services share the common aim of assisting individuals to improve their functioning.

Psychiatric rehabilitation services address the needs of individuals who have a mental illness. Habilitation services enable persons with mental retardation to acquire or improve skills to help them become more independent. Assistive technology helps persons with many different types of disabilities become more self-sufficient. States may offer these services through various options, including an HCBS waiver program. Many types of assistive technology (e.g., motorized wheelchairs, communication devices) are forms of medical equipment and supplies covered under the mandatory home health benefit.

Adaptive Services. In order to remain in their own home or elsewhere in the community, many individuals with physical impairments benefit from home and vehicle modifications.

Home modifications include installing wheelchair ramps, widening doorways, and retrofitting bathrooms and kitchens so that individuals with physical impairments can get around their homes. Vehicle modifications include modifying a car or a van so that a person can get around the commu-

nity. These services can be covered under HCBS waiver programs.

Family and Caregiver Supports. These supports are designed to help the family and friends who provide such enormous support to individuals with disabilities. Various Medicaid options are available to maintain and strengthen these supports.

Respite services to provide relief to the individual's primary caregiver is one of these services. States may also offer training and education services to caregivers, to strengthen their ability to meet the needs of the person they are caring for. These services can be covered under waiver programs. Training and supports may also be offered as component parts of other benefits, such as home health. (Services to support caregivers are discussed in detail in Chapter 8.)

Social Supports. Social supports are intended to help individuals take an active part in both their family and community. Such supports help avoid social isolation.

Social supports such as companion services, for example, provide assistance so that individuals can participate in community activities (e.g., by providing a personal attendant to enable the individual to attend church). These services can be covered only under HCBS waiver programs.

Case/Care Management or Service/Care Coordination. Case management and care coordination services help individuals who need services and supports from several sources. Some of these may be available through a state's Medicaid plan. Some can be obtained through other public programs. Still other supports are available, though possibly harder to access, from private sources.

A common feature of home and community services is the provision of case managers, who may also be called care coordinators or service coordinators. They frequently prepare or facilitate preparation of an individual plan to map out how all the services and supports a person might need will be identified and delivered. Additionally, they play an active role in monitoring the quality and effectiveness of home and community services. Several Medicaid options are available for covering case management and care coordination services. (These options are discussed in detail in Chapter 5.)

As states consider which home and community benefits to offer, and how to offer them, it will help to keep in mind this golden rule: There is no bright line to distinguish "long-term services and supports" from other types of Medicaid benefits. Many benefits not mentioned in this overview are very much a part of the mix required to meet the needs of individuals with disabilities and chronic conditions. For example, individuals who need mobility aids (e.g., power wheelchairs) may find them through a state plan's coverage of medical equipment and supplies. A state plan may also cover many therapeutic services (e.g., occupational and physical therapy) that are also relevant to meeting the needs of many individuals. As a consequence, in crafting effective home and community service strategies, it is important to take stock of other services in the Medicaid state plan and to modify or possibly supplement them if needed. This is to ensure that the coverages chosen address key needs of the persons being served.

As states decide what home and community services and supports to offer, they need to consider certain Federal policy issues and state goals and objectives that constrain, or at least shape, the benefit choices a state can make. The next section addresses the Federal dimension. This is followed by a general discussion of state goals and objectives.

Federal Policy Considerations

As already emphasized, Federal Medicaid law and policy give states considerable latitude in deciding which Medicaid home and community services they will offer, and how. States do not have complete freedom, however. Certain important aspects of Federal policy need to be taken into account to ensure that a state's decisions about what coverages to offer are consistent with Federal requirements and limitations. Seven major Federal considerations merit discussion here. Although they affect state flexibility somewhat, they need not pose serious barriers to devel-

oping effective strategies to support individuals in their homes and communities.

State Plan Requirements. Whether mandatory or optional, services covered under a state's Medicaid plan are subject to two important statutory requirements. First, they must be available on a comparable basis to all Medicaid beneficiaries in an eligibility group in the state who require the service (i.e., the state plan may not offer a service only to persons who have a particular condition or offer it in different forms to different groups). This is called the "comparability" requirement. Second, services must be available statewide (i.e., the state cannot restrict availability of the service to particular geographic regions). This is called the "statewideness" requirement.[2] There are few exceptions to this statewideness requirement. Targeted case management is the major one.

When a state wishes to make home and community services available only to certain distinct groups of Medicaid beneficiaries (e.g., adults who have a physical disability), it must seek Federal approval of an HCBS waiver program. Under such a program both the comparability and statewideness requirements may be waived, to enable states to target services to distinct groups of Medicaid beneficiaries.[3]

Nonduplication. Federal policy provides that a state may not offer precisely the same service under an HCBS waiver program that it offers under its regular Medicaid program. The reason for this prohibition is simple. People who participate in an HCBS waiver program are already eligible, by definition, to receive the full range of services available under the state plan.

HCBS Waiver Coverage to Complement State Plan Coverage. An important exception to the nonduplication requirement for HCBS waiver programs is when the state offers a service under its Medicaid plan with restrictions but offers what are termed "extended" state plan services to provide more complete coverage through an HCBS waiver program.

Some states, for example, cover personal care services under their state plans to provide wide access to this basic assistance and then build on this coverage through waiver programs to provide additional services to specific target populations. States are permitted to use the extended state plan provision to cover the same service in the two programs but in greater amount, scope, and duration of coverage under the latter.[4]

Services That Cannot Be Offered under the State Plan. There are some services a state may not offer under its Medicaid state plan, because they either have not been specified in the authorizing legislation and implementing regulations (which list the services states must or may offer in their Medicaid programs) or may be provided only as a component of institutional services.

An example of the former is respite care (which explains why respite is one of the most common services offered under HCBS waiver programs). An example of the latter is habilitation. Under Federal law and policy, habilitation may be furnished as a state plan service only to residents of ICFs/MR or certain other very limited types of facilities (e.g., rehabilitation hospitals that serve individuals who have had a traumatic brain injury). A state can only offer habilitation services to non-institutionalized persons through an HCBS waiver program.

Service Objective. A state can only offer services that are materially related to the basic reasons a person needs long-term services and supports. This may seem obvious enough, but complicating issues sometimes arise. In the case of HCB waiver services, for example, a state may offer only services that either are necessary for persons to avoid institutionalization or would be available to beneficiaries if they were in a facility. This provision takes no account of other services and supports—such as guardianship services and leisure activities—that might be desirable but cannot be considered necessary given the aims expressed in Federal law. This does not imply that the state is prevented from providing such services and supports. It implies only that Medicaid dollars cannot be used to purchase them.

Room and Board Expenses. Federal Medicaid dollars are not available to pay for the "room and board" expenses (i.e., housing, food, and utilities) of non-institutionalized persons, except in limited

circumstances such as (a) out-of-home respite care, and (b) room and board of a live-in caregiver. Federal financial participation is available for room and board provided as part of respite care furnished in a facility that is approved by the state and not a private residence. Respite care is available as a service under HCBS waivers, but not as a distinct service under the state plan.[5]

The expectation is that individuals will use their own income and resources (e.g., Federal Supplemental Security Income [SSI] benefits and earnings from employment) to meet room and board expenses. This exclusion can complicate development of strategies to support individuals in the home and community. In contrast, room and board expenses are Medicaid-reimbursable in an institutional setting where individuals receive a significantly reduced SSI payment ($30 / month) as a personal needs allowance.

Obligations of Other Public Programs. Medicaid is deemed a payer of last resort. This means that if another public program is obliged to provide a service to an individual, a state generally may not replace this funding with Medicaid dollars. For example, if two public programs such as Medicare and Medicaid cover the same service and an individual is eligible for the service in both programs, Medicare must pay first for the service. Medicaid can only pay once Medicare benefits are exhausted.

State Policy Goals and Objectives

Federal policies provide a framework within which states can weigh their options in deciding whether to offer a service under their Medicaid plan or through an HCBS waiver program. But a state makes its particular coverage choices in light of its own policy goals and objectives. Five major factors need highlighting in this connection.

State Budget Impact. States must balance their budgets on a regular basis—every year for most states. This can make a state wary of offering services under its statewide Medicaid plan, because Federal law prohibits rationing the amount of services furnished to individuals or limiting the number of persons who receive the service under that plan (as noted in the section on Federal policy considerations above).

Thus, states are understandably careful that the costs of offering a service under the state plan not significantly exceed available resources, because they are uncertain both about how many individuals might qualify and about how much it might cost to serve each person. One reason many states have turned to HCBS waiver programs to expand availability of non-institutional long-term care services is that the amount they will spend in the waiver context is predictable. This is because a state that offers services under an HCBS waiver program is obligated to serve no more than the number of beneficiaries the state itself establishes.

Inclusiveness. While state officials and policymakers must be concerned about expenditures, it is often equally important to them that services be available to all who require them. This is an argument against providing services through waivers and can lead states to cover a particular service under the state plan in order to ensure universal access. As discussed below, when deciding whether to cover a service under the state plan or a waiver program or both, states need to carefully consider how services provided in different programs can complement each other in providing people with disabilities the right service mix and amount.

Target Populations. Because services offered under a Medicaid state plan must be provided to all eligible individuals on a comparable basis, it can be difficult to vary services or service delivery approaches based on the needs of individuals who have particular impairments and specialized needs. In addition, it is sometimes easier for a state to craft a package of services and supports to meet the needs of specific groups than to seek a one-size-fits-all state plan coverage design.

These considerations frequently lead a state to select an HCBS waiver program as a vehicle for offering services to defined groups of individuals, because the service package can be fine-tuned to meet their distinct needs.

Maintaining a Unified Service Delivery System. While Medicaid is the major funding source for home and community services, it is frequently not

the only one. In many states, distinct state-funded service systems or networks have evolved for specific target populations—individuals who are elderly, who have a serious mental illness, or who have a developmental disability, for example. One group for which states have historically not developed specific programs or service systems is persons ages 18 to 64 who have physical disabilities—a group that is frequently underserved.

These state-funded service systems often play a crucial role in expanding home and community services for the groups they serve. But they vary considerably in the types and amounts of services they provide and the numbers of people they serve. It is important to maintain these service systems. But it is also important to ensure that they are integrated into a unified service delivery system for their particular target group. An effective way of achieving this integration for many states is the targeted approach permitted under a waiver program. This is a way of accessing Medicaid funding at the same time as ensuring consistency in financing and practice across an array of funding sources.

Eligibility. As discussed in Chapter 2, a state can qualify a wider range of individuals for Medicaid using an HCBS waiver program than it can under its state plan. Many individuals who might not qualify for Medicaid benefits through the state plan by virtue of their income, in particular, may be eligible for services under an HCBS waiver program.

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The following two sections, respectively, provide detailed descriptions of the home and community services that can be provided (a) under the Medicaid state plan and/or (b) through HCBS waiver programs.

Home and Community Services under the Medicaid State Plan

Federal law distinguishes between services offered under a Medicaid state plan and services that may be offered when the Secretary of HHS—operating through HCFA—grants waivers for a state to operate an HCBS waiver program. The services that can be offered without a waiver are called Medicaid state plan services. Some of these (e.g., home health care) must be provided by every state that operates a Medicaid program. These are called mandatory services.[6] Others can be provided at state option. These are called optional services.

When a state covers a service under its Medicaid state plan, it may impose limits on exactly what will be provided and under what circumstances. Such limitations take three forms: (1) how often a person may receive a service (amount), (2) for how long (duration), and (3) the exact nature of what is provided (scope). But Federal law requires that such limitations not undermine a person's receipt of necessary assistance. Any limitations states establish generally must be based on clinical grounds. Limits must be sufficient to meet the needs of most people most of the time, but there is no requirement that states must meet all needs of all beneficiaries at all times.

A state's decision to offer an optional service under its Medicaid state plan amounts to a decision to make the service available to all individuals who require it, within whatever limitations on amount, scope, and duration the state may have established. This is why Medicaid beneficiaries are said to be "entitled" to state plan services.[7] A state has the option of covering under its state plan four main home and community services that are especially important for persons with disabilities: (1) personal care; (2) targeted case management; (3) clinic; and (4) rehabilitative services.

Personal Care/Personal Assistance

Prior to enactment of the Omnibus Reconciliation Act of 1993 (OBRA 93), personal care services offered through the state plan were limited in scope and had a medical orientation, due to the requirement that they be authorized by a physician and supervised by a nurse. OBRA 93—and implementing regulations effective in November 1997—gave states the option of substantially broadening the scope of personal care services, to furnish individuals a wide range of assistance in

everyday activities both in and outside the individual's home.[8]

In January 1999, HCFA released a State Medicaid Manual Transmittal that updated the Agency's guidelines concerning coverage of personal care services. In it, HCFA made clear (a) that personal care services include assistance with both ADLs and IADLs, and (b) that personal care for persons with cognitive impairments may include cueing along with supervision to ensure the individuals perform the task properly. Formerly such supervision generally was considered outside the scope of personal care. (See Appendix II for the complete text of HCFA's guidance on this issue.)

A state may now extend such services to include supervision and assistance to persons with cognitive impairments, which can include persons with mental illness or mental retardation as well as persons who have Alzheimer's disease and other forms of dementia. However, this supervision and assistance must be related directly to performance of ADLs and IADLs. Simple companionship or custodial observation of an individual, absent hands-on or cueing assistance that is necessary and directly related to ADLs or IADLs, is not a Medicaid personal care service. In particular, the Manual states:

> *Scope of services—Personal care services covered under a state's program may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cueing so that a person performs the tasks by him/herself. Such assistance most often relates to performance of ADLs and IADLs. . . . Personal care services can be provided on a continuing basis or on episodic occasions. Skilled services that may be performed only by a health professional are not considered personal care services.*

However, skilled services may be provided under a state's personal care benefit under the state plan when they are delegated by a nurse and when the practice is recognized and permitted under state law. (Nurse delegation is discussed in detail in Chapter 7.)

> *Cognitive impairments—An individual may be physically capable of performing ADLs and IADLs but may have limitations in performing these activities because [of] a cognitive impairment. . . . Personal care services may be required because a cognitive impairment prevents an individual from knowing when or how to carry out the task. For example, an individual may no longer be able to dress without someone to cue him or her on how to do so. In such cases, personal assistance may include cueing along with supervision to ensure that the individual performs the task properly.*

In October 1999, HCFA further revised the Manual to permit states to offer the option of consumer-directed personal care services. The Manual revisions explicitly recognized that provision of personal assistance services may be directed by the persons receiving such service, including those persons' own supervision and training of their personal care attendants. In particular, the Manual states:

> *Consumer-directed services—A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of personal care services, and, if necessary, fire the provider. The State Medicaid Agency maintains responsibility for ensuring the provider meets State provider qualifications . . . and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the State may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services.*[9]

These manual materials describe a robust scope of personal care / personal assistance services a state may choose to cover under its Medicaid state plan—in keeping with contemporary views con-

cerning the role personal assistance can play in supporting individuals with disabilities in a wide range of everyday activities. As a result of the changes made in Federal policy, there is now little difference in the scope of personal care services that may be offered under the Medicaid state plan and those that may be offered under an HCBS waiver program. In many states, consumer direction of personal care services has been a feature of personal assistance programs (both under Medicaid and funded with other dollars) for many years. For example, consumer direction was built into the Massachusetts Medicaid personal care program from its inception. HCFA materials clearly acknowledge and sanction this model. HCFA has also expressed a strong interest in identifying and working with the states to eliminate any further barriers to implementation of CD personal assistance service models in Medicaid. (Chapter 7 discusses this topic in greater detail, with respect to both CD personal assistance services and self-determination for people with developmental and other disabilities.)

However, neither the provisions of OBRA 93 nor the revised Federal regulations and HCFA State Medicaid Manual guidelines require a state to change the scope of its pre-1993 coverage. In order to take advantage of these changes, a state must file an amendment to its Medicaid plan.

Expenditure Ramifications

Twenty-seven states and the District of Columbia cover personal care services under their Medicaid state plans, but only a few states make it broadly available.[10] The principal reason why many states do not cover personal care services at all, or impose considerable restrictions on the services they offer, is concern about controlling expenditures for such services. State officials often want to know: (1) How many Medicaid beneficiaries will qualify to receive the service? (2) How much service will they use once eligible?

Advocates for personal care/personal assistance point out that personal care services are usually less costly than institutional services and, consequently, that adding this coverage will result in lower institutional expenditures—by avoiding or delaying admission of individuals to institutional

Special Personal Assistance Issues, Whether under State Plan or an HCBS Waiver Program

Delegation of Nursing Tasks. Certain personal assistance activities (e.g., medication administration, tube-feeding) fall under the jurisdiction of states' Nurse Practice Acts. Hence, even though Federal law has "de-medicalized" its rules concerning personal care services, state Nurse Practice laws still may dictate close involvement of medical personnel. In such cases, states often restrict delivery of personal care services to home health agencies. In these states, changes to the Nurse Practice Acts would be necessary to take full advantage of the flexibility afforded by Federal provisions for personal care services. (Nurse delegation is discussed in detail in Chapter 7.)

Provider Qualifications. More and more states are routinely requiring individuals who would provide personal care services to undergo criminal background checks and checks against abuse/neglect registries. States also typically require such individuals to have completed a basic training course. To ensure proper supervision of personal care workers, some states require that they be employed by agencies that hire the workers and supervise them. Others permit individuals to furnish personal care in their own right, with the consumer responsible for oversight (including deciding whom to hire). Still others charge case management authorities with oversight and monitoring responsibilities. (Chapter 7 provides a detailed discussion.)

Payment of Family Members. HCFA policy states that:

> Personal care services may not be furnished by a member of the beneficiary's family. . . . HCFA defines family members as spouses of beneficiaries and parents (or step-parents) of minor beneficiaries. HCFA believes this to be the preferred definition as this definition is identical to the one that applies to personal care services provided under an HCBS waiver.

Based on the foregoing, non-spousal and non-parental relatives not legally responsible for the beneficiary's care may provide such services for pay if the state chooses. (Chapter 8 provides a detailed discussion.)

facilities as well as enabling institutionalized persons to return to their homes and communities. However, some observers are concerned that such savings might be offset by the effect of more people overall seeking services once their availability became known (i.e., increased demand.) The costs of meeting the needs of more people could offset the savings stemming from reduced nursing facility usage. Both are legitimate points. The challenge for state policymakers and disability advocates is to strike a balance while addressing each.

A few states operate relatively extensive Medicaid personal care programs (e.g., New York, California, and Texas). Elsewhere, provision of such services is more limited.[11] Many states that offer personal care have strict limitations on its delivery. Some either stringently regulate the amount of personal care services an individual can receive or cap the dollar value of such services at a level well below the cost of nursing facility services.[12] Others limit eligibility for personal care services by identifying a population or level of functional limitation for which they will provide assistance. However, states must be careful not to violate Medicaid comparability requirements by restricting services to those with a particular diagnosis or condition, such as by making benefits available only to people who use wheelchairs, or to people who are likely to require nursing facility services. Nine states provide personal care services only to the categorically eligible.[13] A few states do not include personal care in their state plan, but provide this service to children covered by the EPSDT mandate.

A major financial issue that can arise is whether state payment rates are adequate to recruit enough personal care workers and attendants to meet demand. Expenditure concerns, as noted earlier, have prompted many states to turn to an HCBS waiver program to secure Medicaid financing of personal care assistance services, since the waiver program permits tighter cost and use limits. Table 4-1 summarizes the differences in personal care service coverage between state plan and HCBS waiver programs.

Targeted Case Management

States can amend their state plans to cover case management services for specified groups of

Table 4-1. Differences in Medicaid Coverage of Personal Care Services

Issue	Personal Care Option	1915(c) Waivers
Entitlement	If included in the state plan, states must provide services to all categorically eligible Medicaid beneficiaries who demonstrate a medical need for the service.	States can limit the number of people served in the waiver program. But once the person is determined eligible for the program and enrolled, a state may not deny a waiver-provided service for which the person has an assessed need.
Functional Criteria	Beneficiaries must have functional limitations that result in a need for the services covered.	Beneficiaries must meet the minimum institutional level of care criteria.
Financial Criteria	Beneficiaries must meet community financial eligibility standards.	State may set financial eligibility criteria up to 300 percent ($1536) of the Federal SSI payment standard ($512).
Services	Services include only those specified in the Federal definition of personal care services.	Coverage can include a very broad array of state-defined services.

Medicaid beneficiaries without making such services available to all beneficiaries (hence, the term "targeted").[14] Targeted case management services are exempt from the comparability requirement and can also be offered on a less than statewide basis.[15]

States are free to define the groups to whom they will provide targeted case management services and there is no limit on the number of groups who may receive such services. For example, a state may have a distinct coverage for Medicaid beneficiaries who have a developmental disability and another distinct coverage for those who have a mental illness. And the statute expressly provides that a state may offer these services to individuals with acquired immune deficiency syndrome (AIDS) or with AIDS-related conditions. Target groups states have established include:

- Persons with developmental disabilities (as defined by the state)
- Children from birth to age 3 who are experiencing developmental delays or behavioral disorders as measured and verified by diagnostic instruments and procedures
- Children from birth to age 21 who have chronic health conditions
- Persons with severe and persistent mental illness as defined by the state
- Pregnant women and infants up to age 1
- Individuals with hemophilia
- Individuals 60 years of age or older who have two or more physical or mental diagnoses that result in a need for two or more services
- Individuals with AIDS or HIV-related disorders
- Persons being transitioned from nursing homes to the community.

A state may define a target population broadly (e.g., all Medicaid-eligible individuals with a developmental disability) or more narrowly (e.g., Medicaid-eligible individuals with a developmental disability who also have a mental illness). Although the targeting aspects of this case management coverage make it somewhat akin to the HCBS waiver program, there is one important difference. As with any other state plan service, once a state has established its target population, case management services must be furnished to all eligible individuals. A state may not limit the number of eligible individuals who may receive these services.

States do have the option of limiting the entities that may furnish targeted case management services to individuals with a developmental disability or a mental illness. This provision enables states to tie provision of these services to the "single point of entry" systems common in state service systems that serve these populations, so that states can maintain a unified approach to service delivery. (See Chapter 9 for a discussion of single point of entry systems.)

The services a state offers under targeted case management can be described as "planning, linking, and monitoring" provision of direct services and supports obtained from various sources (the Medicaid program itself, other public programs, and a wide variety of private sources)—making their scope very broad. Examples that HCFA cites include assistance in obtaining food stamps, energy assistance, emergency housing, and legal services. Permitted activities can also include service/support planning (including assessment) and monitoring delivery of direct services and supports in order to ensure they are meeting the person's needs.

Although a wide range of activities on behalf of beneficiaries can be included within the scope of targeted case management, some cannot. In particular:

- Activities related to authorization and approval of Medicaid services.[16]
- Activities related to making basic Medicaid eligibility determinations.
- Activities that constitute "direct services" to the consumer. For example, the activity of transporting an individual to and from a doc-

tor's appointment is outside the scope of targeted case management. To the extent that this activity is necessary, it could be paid for as a Medicaid state plan service rather than as a targeted case management service. The person's case manager may certainly transport the individual to a physician's appointment. Although the costs involved cannot be claimed as case management (because the service is direct), they may be reimbursed as a transportation service under the Medicaid state plan or as an administrative expense.[17]

- Activities provided to institutionalized persons. This restriction is based on two Federal provisions: (a) Federal regulations concerning Medicaid institutional services require that facilities provide care coordination services to residents and (b) Medicaid prohibits duplicate payments for the same service. However, targeted case management services may be provided to institutionalized persons in the last 180 consecutive days of a Medicaid-eligible person's institutional stay, if provided for community transition. (Chapter 6 discusses transition issues in detail.)

- Activities that overlap or duplicate similar services a person receives through other means. For example, home health agencies are required to develop care plans for the individuals they serve. Targeted case management services cannot include development of these care plans. But they may include ensuring that the care plans are carried out and meet the consumer's needs.

While the activities listed above are not reimbursable under the targeted case management option, they are often billable under other options—such as clinical case management that is part of a service or administrative case management.

As this list makes clear, limitations on the scope of targeted case management services revolve mainly around avoiding duplication with other activities—either that the single state Medicaid agency must conduct in any case, or that are more properly claimed and reimbursable as direct services under the Medicaid state plan.

Because targeted case management can be provided to a larger number of Medicaid beneficiaries than are served under an HCBS waiver program, many states dropped case management from their HCBS waiver program once targeted case management became a state plan option. The majority of states have now dropped coverage of case management for persons with developmental disabilities under their HCBS waiver programs in favor of the state plan option.

Case management and service coordination are common features of home and community service systems in most states. Hence, there is a good fit between this coverage option and how states have organized their home and community service delivery systems. Targeted case management services can be made available to persons who qualify for a state's HCBS waiver program (in lieu of providing such services under the waiver program) as well as for individuals who do not participate in the waiver program.

Some states cover case management services under their HCBS waiver programs and use the targeted case management option for Medicaid beneficiaries not receiving waiver services. For example, Wyoming covers case management services in its HCBS waiver programs for adults and children with developmental disabilities, and makes targeted case management services available to individuals who have been wait-listed for the waiver services.

Clinic Services[18]

Especially for individuals who have a mental illness, states have the option of covering specialized treatment services and other supports under several state plan benefits. The two benefits states most frequently cover are the optional clinic benefit and the optional rehabilitative services benefit. States employ the clinic option for a wide variety of purposes in their state Medicaid programs, including paying for services furnished through health-care clinics and community mental health centers. The clinic option also serves as a means of paying for mental health services furnished to Medicaid beneficiaries on an outpatient basis. Mental health clinics may provide mental health

therapy and other treatment to Medicaid beneficiaries—services needed by people who have serious and persistent mental illness and need long-term care services and supports to remain in their communities. The clinical services provided through the clinic option must be site based and supervised by a physician.

Rehabilitative Services[19]

The rehabilitative services option allows states more flexibility to design service packages than does the clinic option, because of its broad definition in Federal regulation: "any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under state law, for maximum reduction of physical or mental disabilities and restoration of a recipient to his/her best functional level."

Rehabilitative services can include services also covered under the clinic option. But unlike services under that option, they are portable (i.e., not limited to specific sites under the direct, on-site supervision of a physician). Many other services also fall within the scope of rehabilitative services. Psychiatric rehabilitation services include basic living skills training (including independent living skills and cognitive skills, as well as education regarding medications and medication management), social skills training, counseling and therapy, and collateral services (consultation with and training of others, including family members, primary caretaker, providers, legal guardians or other representatives, and significant others). Such training and counseling is limited to activities that directly support the individual.[20]

Collateral services can be covered as a specific stand-alone category or as part of day treatment or intensive in-home services. Through this activity, reimbursement is provided for face-to-face encounters with people who are important in the beneficiary's life, when those encounters are needed to develop or implement the rehabilitation plan.

Psychiatric rehabilitation services are furnished in a variety of locations, including homes, partial hospitalization or day programs for adults, day

How States Use the Rehabilitative Services Option

South Carolina. Mental health services are dually covered under the clinic and rehabilitation options and are targeted to adults with psychiatric disability and children with serious emotional disturbance. The state uses these two options to cover a wide range of services including:

- Assessment services
- Case consultation
- Crisis intervention and management
- Individual, family, and group therapy
- Rehabilitative psychosocial therapy
- Intensive in-home services
- Family preservation services
- Treatment planning
- Care coordination
- Youth crisis treatment
- Medication compliance activities
- Psychiatric medical assessment
- Restorative independent living skills
- Therapeutic foster care services
- Children's day treatment (including behavior/emotional evaluation, role performance and functioning, family functioning, and social and behavioral intervention).

California. The state covers a wide range of mental health services, in-home services, and collateral services. Rehabilitation services for children with serious emotional disturbances are designed to assist the child/adolescent in gaining the social and functional skills necessary for appropriate development and social integration. These services can be provided in any setting, including residential placements. Intensive day treatment is often integrated into an education component and can be full- or half-day.

Illinois. Among other services, the state covers individual/family social rehabilitation, which involves structured activities to improve social, emotional, cognitive, interpersonal, or community-adaptive functioning.

treatment programs in schools or other locations for children, and residential placements (including facilities of less than 16 beds, such as group homes or therapeutic foster care homes). Crisis services and early intervention services, including services for very young children exhibiting signs of serious emotional disorders, are also furnished under this option.

These services, along with personal care and targeted case management, can be combined to meet a wide range of service and support needs for persons who have a mental illness. Of the 35 states that use the rehabilitative services option, 25 also provide targeted case management services to such persons.[21]

The clinic and rehabilitative services coverage options are not generally used to provide long-term care services and supports to individuals with disabilities other than mental illness. During the 1970s and 1980s, a few states secured HCFA approval to cover daytime services for persons with mental retardation and other developmental disabilities under either the clinic or the rehabilitative option. However, the Agency ultimately ruled that the services being furnished were habilitative rather than rehabilitative and consequently could not be covered under either option.

Congress acted in 1989 to permit states that had secured HCFA approval of these coverages to continue them but effectively prohibited other states from adding such coverage. The main basis for HCFA's ruling was that habilitative services could be furnished only to residents of ICFs/MR under the state Medicaid plan or through an HCBS waiver program for individuals who might otherwise be eligible for ICF/MR services. A few states have maintained their coverage of these services. But many have dismantled their coverages in favor of offering similar services through their HCBS waiver programs.

Services That May Be Offered under a Home and Community Based Services Waiver Program[22]

In waiver programs states have the greatest flexibility to design programs that meet the unique needs of individuals with disabilities. To assist states in submitting requests to begin waiver programs, HCFA issued a standard HCBS waiver application format in the early 1990s. This standard format now includes HCFA-suggested definitions of a wide range of services states may use to specify what their waiver programs will cover. Many of these suggested service definitions evolved from services that specific states proposed and HCFA approved in the past.

But the services a state may offer under waiver authority are by no means limited to definitions in the standard format. In using the standard format, a state is free to accept the HCFA definition as is, modify it to reflect other activities and considerations important to the state, and/or propose a new service entirely. Many states use the HCFA definitions (often with modifications). But many others have proposed alternative definitions to ensure the service description matches what they really have in mind.

Some States Operate Many Different Programs

Collectively, the 50 states operate about 250 distinct HCBS waiver programs. For example, Colorado operates ten such programs: five distinct waiver programs for individuals with developmental disabilities, one for people with mental illness, one for individuals who have had a brain injury, one for persons with AIDS, one for the "elderly, blind, and disabled," and a final one for children who are medically fragile.

Because the HCFA service definitions may not be a perfect match for what a state wants—and because HCFA requires a precise definition of what will be furnished to waiver participants[23]—it is best to begin by developing a clear understanding of what the state intends. This analysis should encompass the types of services and supports to be delivered, as well as how, where, and by whom. Gaining a comprehensive understanding of its objectives puts a state in a good position to decide how well the definitions in the standard format "fit." A good rule of thumb in considering

How Michigan's HCBS Waiver for People with Developmental Disabilities Defines Supports Coordination

"Supports Coordination involves working with the Waiver participant, and others that are identified by the participant such as family members, in developing an Individual Plan of Supports/Services. Utilizing person-centered processes (including planning), support coordination assists in identifying and implementing support strategies. Support strategies will incorporate the principles of empowerment, community inclusion, health and safety assurances, and the use of natural supports. Support coordinators will work closely with the participant to assure his or her ongoing satisfaction with the process and outcomes of the supports, services, and available resources.

"Supports coordination means face-to-face and related contacts including activities which assure that: the desires and needs of the participant are determined; the supports and services desired and needed by the participant are identified and implemented; housing and employment issues are addressed; social networks are developed; appointments and meetings are scheduled; person-centered planning is provided; natural and community supports are utilized; the quality of the supports and services as well as the health and safety of the participant are monitored; income/benefits are maximized; activities are documented; and plans of supports/services are reviewed at such intervals as are indicated during planning."

HCFA-predefined coverage is: "If it fits, use it. If it almost fits, change it to fit. If it doesn't fit at all, propose a new service."

Coverages Included in the Standard HCBS Waiver Application Format

This subsection describes the HCBS waiver service options included in the standard HCBS waiver application format. This discussion, with very few exceptions, follows the order in which these services are listed in the standard format. It groups them, for easy reading, into seven service categories. (Consult Appendix I for complete definitions of all the services included in the standard format, with relevant requirements and restrictions.)

Case management/care coordination services

Case management: Assistance in gaining access to needed waiver and other state plan services, as well as needed medical, social, educational, and other services, regardless of the funding source for the services to which access is gained.

Activities performed under this definition may include: (a) assessment; (b) service/support planning; (c) arranging for services; (d) coordinating service providers; (e) monitoring and overseeing provision of HCBS waiver and other services furnished to the participant; and (f) helping individuals gain access to non-Medicaid services.

States may choose to have case managers conduct routine monitoring of services and to initiate and oversee the assessment and reassessment of the individual's level of care. Alternatively, they can choose to have these activities performed by another entity.

Case management services are a typical component of HCBS waiver programs regardless of target population.[24] States that do not include case management as a service under their HCBS waiver programs typically furnish such services either through the targeted case management option under the Medicaid state plan or as an administrative activity. (Chapter 5 discusses each of these options in detail.)

Personal care/personal assistance services

This service grouping includes services usually furnished to individuals who live in their own home or the family home. But they can be furnished to people who have other living arrangements as well. The services have some differences, but all revolve mainly around provision of personal assistance in performing ADLs or IADLs. These services may be provided anywhere in the community, not just in a person's home.

Homemaker: Assistance with general household activities—meal preparation, cleaning, grocery

shopping, and other routine household tasks—provided by a trained homemaker.

Homemaker services are a subset of personal assistance services, furnished when there is no other means of attending to general household activities. Generally homemakers do not provide assistance with ADLs. However, the same person may provide both personal assistance and homemaker tasks and many persons with disabilities prefer such an arrangement. Coverage of homemaker services is most common in HCBS waiver programs that serve elderly individuals, although it is sometimes included in programs serving other populations as well. Homemaker services may not be covered under a state's Medicaid plan on a stand-alone basis; they may be provided only as an adjunct to personal care services furnished under the Medicaid state plan.

Home health aide services: These are the same services provided under Medicaid's home health benefit, except that limitations on the amount, duration, and scope of such services imposed by the state's approved Medicaid plan are not applicable.

Home health aide services do not have to be provided by a home health agency. States are free to define home health aide services using different criteria (e.g., services provided by certified nurse assistants). Cost concerns lead many states to restrict the amount of home health aide services provided through Medicaid's mandatory home health benefit. For example, a state may impose a maximum number of hours a week for home health aide services. Under a waiver program, a state may permit a greater amount of such services, subject to the waiver cost cap. However, they must be in addition to services provided under the state plan.

Personal care services: Assistance with eating, bathing, dressing, personal hygiene, and other ADLs. May include assistance with meal preparation. May also include such housekeeping chores as laundry, bedmaking, dusting, and vacuuming, which are incidental to the assistance provided or essential to the health and welfare of the individual (rather than the individual's family).

This definition parallels the scope of personal care services that may be furnished under the Medicaid state plan. States frequently broaden the standard waiver definition to include assisting the individual with IADLs and with participation in activities outside the individual's home. A state may cover personal care services under both its state plan and an HCBS waiver program. But to do so it must demonstrate that the proposed HCBS waiver coverage is different from—or in addition to—services in the state plan (as discussed in the section on Federal policy considerations earlier in this chapter).

States may choose whether members of the person's family (excluding spouses and parents of minor children) may serve as providers of personal care. If a state chooses to allow family members to provide services, it may either require them to meet the same qualifications as other individuals providing such services or apply different stan-

A Frequent Problem in Designing Waiver Coverages: Tendency to Tie Them to Particular Service Settings

In designing HCBS waiver programs it is helpful to remember that services can be furnished in both the home and a wide range of community settings. Historically, in developmental disabilities services, for example, states have tended to identify "day habilitation" with particular sites. This has had the effect of preventing habilitation services from being furnished to individuals in everyday community settings where training could be used to assist the individual in mastering skills important in community life. Several states are now removing the ties of this service to specific sites.

Another example of problems that can be caused by tying a service to a particular setting can be found in the area of personal care/personal assistance. Personal care can be defined in a way that ties its delivery to a person's living arrangement. But it can also be defined more flexibly, to permit provision of personal assistance in both the home and other community settings (as in the case of Michigan's HCBS waiver program for people with developmental disabilities). Defined in this alternative fashion, personal assistance services can be furnished more flexibly and more in accordance with the individual's particular needs and preferences.

dards. HCFA policy guidelines generally discourage use of family members as providers of personal care services, except to the extent other providers are not available or special circumstances exist. States may also choose by whom and how frequently personal care services will be monitored. (See Chapter 8 for guidelines related to the payment of family members.)

Personal care services are found in nearly all HCBS waiver programs, irrespective of target population. They are the main vehicle states use to furnish services and supports to individuals living in their own homes who need either direct assistance in performing ADLs and IADLs or help in performing everyday household activities.

In some instances, these services are furnished to individuals who reside in living arrangements owned or managed by provider agencies—including foster living arrangements and group living arrangements. In these cases, Medicaid funding can be used along with other resources to meet the costs of supporting the individual in that living arrangement. In other words, the "personal care" component of the service is qualified for Medicaid funding under the HCBS waiver program. (See Chapter 5 for a detailed discussion.)

> *Chore services: Services needed to maintain the home in a clean, sanitary, and safe environment. This service includes heavy household chores such as washing floors, windows, and walls; tacking down loose rugs and tiles; and moving heavy items of furniture to provide safe access and egress.*

Chore services are distinguished from homemaker services by their sporadic nature and the fact that they generally require more effort or skill to perform. Coverage of chore services is typically found in HCBS waiver programs serving older persons and/or persons with physical disabilities. Chore services may be provided only as an adjunct to provision of personal care services under the state plan (not on a stand-alone basis under that plan).

> *Attendant care services: Hands-on care, of both a supportive and health-related nature, which substitutes for the absence, loss, diminution, or impairment of a physical or cognitive function. This service may include skilled nursing care to the extent permitted by state law. Housekeeping activities incidental to the performance of care may be furnished as part of this activity.*

Attendant care services are similar in scope to personal care services, although they may include greater emphasis on addressing the health care needs of beneficiaries. States may choose to have the attendant supervised by a nurse or by the beneficiary. Attendant care services are most commonly covered in HCBS waiver programs for people with physical disabilities, although they are covered in programs that target other groups as well. For example, Iowa's HCBS waiver program for persons with mental retardation includes coverage of "consumer-directed attendant care." Attendant care services may be furnished on a stand-alone basis under the Medicaid state plan when they are defined as personal care/personal assistance services.

Services usually furnished in settings other than a person's home

States employ HCBS waiver funding to underwrite a portion of the costs of supporting a person in living arrangements other than the person's home. Typically, HCBS waiver dollars underwrite the non-room and board component of these living arrangements, including personal care, training and supervision, as well as the provision of other services. Since HCFA's coverage definitions anticipate that individuals will receive various types of supports in such living arrangements, using these definitions avoids having to make separate payments for each distinct type of activity.

> *Residential habilitation: Assistance with acquisition, retention, or improvement in skills related to ADLs (which, as noted earlier, states can define as they choose), such as personal grooming and cleanliness, bed making and household chores, eating and preparation of food, and social and adaptive skills necessary to enable the individual to live in a non-institutional setting.*[25]

States have the option of covering habilitation services in two major ways: residential habilitation and day habilitation (described in the next major service category). Residential habilitation

combines habilitation, personal care, and supervision into a single service and is most commonly employed in HCBS waiver programs for persons with mental retardation and other developmental disabilities who are served in group homes or similar living arrangements. But residential habilitation services may also be furnished to individuals who have their own living arrangement. In covering residential habilitation services, a state may also include transportation services furnished on behalf of residents within the scope of the residential services (rather than covering such services separately). Room and board costs associated with furnishing residential habilitation services are not eligible for Medicaid funding.

Habilitation services (whether day or residential) may not be furnished under the Medicaid state plan except to individuals who are residents of ICFs/MR. Habilitation services outside an ICF/MR may only be furnished through an HCBS waiver program.

> *Adult foster care: Includes personal care and services, homemaker, chore, attendant care, companion services, and medication oversight (to the extent permitted under state law) provided in a licensed (where applicable) private home by a principal care provider who lives in the home.*

Adult foster care involves the provision of services and supports to individuals who live in the home of a non-relative caregiver responsible for meeting the individual's personal care and other needs.[26] Typically these living arrangements are made available to individuals with physical disabilities or who are elderly, although many states also use such living arrangements to support people with developmental disabilities in the community. Using this service definition enables states to pull all these services together into a single coverage (rather than covering each activity as a distinct service).

> *Assisted living: Personal care and services, homemaker, chore, attendant care, companion services, medication oversight (to the extent permitted under state law), and therapeutic social and recreational programming provided in a home-like environment in a licensed (where applicable) community care facility in conjunction with residence in the facility.*

States that cover assisted living in a waiver program can pull together under a single coverage a wide variety of services and supports (including health and therapeutic services) that are furnished to individuals who live in "assisted living" centers. (Coverage of assisted living is discussed in detail in Chapter 5.)

Specialized, disability-related services

Various specialized services may be furnished under an HCBS waiver program. These services, which can be provided to individuals with specific conditions and impairments, are usually furnished away from the individual's living arrangement. They include: (a) day habilitation and "extended habilitation" services; (b) adult day health services; and (c) mental health services.

> *Day habilitation: Assistance with acquisition, retention, or improvement in self-help, socialization, and adaptive skills to enable individuals to attain or maintain their maximum functional level.*

Day habilitation services are covered by nearly every state that operates an HCBS waiver program for people with mental retardation and other developmental disabilities. Generally, such services are furnished at a facility in the community. However, a growing number of states are encouraging provision of these services in other community locations, to promote community integration and improve the relevancy of skill training. Transportation services may be included in the scope of day habilitation services.

Although states have historically provided habilitation services under an HCBS waiver only to individuals with mental retardation or related conditions that occurred before age 22, neither Medicaid law nor implementing regulations restrict who may receive habilitation services in an HCBS waiver. Other individuals who do not have mental retardation or related conditions, such as persons with traumatic brain injury or other physical disabilities that occurred after age 22, may also benefit from habilitation services under the waiver. Accordingly, states may provide habilitation services—including the expanded habilitation services of educational, prevoca-

tional and supported employment services—under an HCBS waiver to people of all ages who qualify for the waiver. (See Appendix II for the complete text of HCFA's guidance on this issue.)

> *"Extended Habilitation Services."* Extended habilitation services include (a) prevocational services, (b) educational services, and (c) supported employment services.[27] In 1986, Congress amended the HCBS waiver statute to enable states to offer "extended" habilitation services. These services have traditionally been provided only to individuals with mental retardation and other developmental disabilities. However, recent HCFA guidance has clarified that they may also be offered to other groups who can benefit from them, such as persons who have had brain trauma or acquired brain disorder. (See Appendix II for the complete text of HCFA's guidance.)

Extended habilitation services can be combined with one another and with day habilitation to support individuals in a variety of ways (i.e., provision of one type of habilitation service does not exclude provision of others). But none of the extended habilitation services provided through HCBS waiver programs can be reimbursed if they are available through programs funded under either the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (IDEA). States must document that these services are not available through those programs.[28]

(a) Prevocational services encompass assistance aimed at preparing an individual for paid or unpaid employment. The preparation is not job-task oriented. Rather, it includes teaching such concepts as compliance, attendance, task completion, problem solving, and safety. Prevocational services concentrate on skill training individuals might require to secure employment—including training directed to work goals such as improvements in attention span and motor skills (rather than explicit employment objectives). Medicaid law does not permit a state to offer what are termed "vocational services" (with the single exception of supported employment services, as discussed below)—making the definition of prevocational services decidedly habilitative.[29]

With respect to individuals with developmental disabilities, prevocational services cannot be provided under the Medicaid state plan except to residents of an ICF/MR. A state may include in the scope of these services costs of transportation to and from the site at which this training takes place. About three-quarters of the states operating HCBS waiver programs for people with developmental disabilities offer this service, generally at fixed sites in the community.[30]

(b) Educational services encompass special education and related services as defined in IDEA, to the extent they are not available under an IDEA-funded program. These services may be furnished as supplements to special education services provided to school-age individuals. But they may also be defined in an alternative way that can include education and training for adults no longer receiving special education services. Very few states offer educational services in their HCBS waiver programs.

(c) Supported employment services include those activities needed to sustain paid work by individuals receiving waiver services, including supervision and training. Supported employment services and supports may be offered to individuals when needed to obtain and maintain a job in the community regardless of the wage they earn. As with all waiver services, states may use their own definition of supported employment as long as the intent of the service is to assist individuals to obtain and maintain employment. In some states, provision of supported employment services is coordinated between the state vocational rehabilitation authority (which underwrites initial training costs) and the developmental disabilities program (which provides "follow-along" services through the HCBS waiver programs).

The services states offer under this coverage include "job coaching," which enables an individual to learn how to perform a job at a community employment site. Extended habilitation services may also include transportation costs associated with the person's getting to and from the job site, adaptive aids and equipment necessary for the person to secure a job, and other supports. Supported employment services may not be furnished under the Medicaid state plan except to

individuals who reside in ICFs / MR.

Adult day health: Health, therapy, and social services needed to ensure an individual's optimal functioning, furnished in an outpatient setting, four or more hours per day on a regularly scheduled basis, for one or more days per week.

These services are generally provided to older persons at senior centers or similar community facilities. Most states require that adult health programs have medical personnel available on site to address health care needs. Coverage of these services is nearly universal in HCBS waiver programs that serve seniors with severe impairments.

Supported Employment Services in Colorado's HCBS Waiver Program for People with Developmental Disabilities

The following are included in Colorado's supported employment services:

- Individualized assessment that may include community orientation and job exploration
- Individualized job development and placement services that produce an appropriate job match for the individual and his/her employer
- Ongoing support, training, and facilitation in job finding, job skill acquisition, job retention, career development, and work-related activities
- Intervention and training needed to benefit from supported employment services and other supports that would help remove or diminish common barriers to participation in employment and to the building of community relationships.

As a component of adult day health services, states have the option to cover transportation between the individual's place of residence and the adult day health center.

Services for individuals with serious persistent mental illness

A state may cover three specialized services for individuals who have serious persistent mental illness: (a) clinic services; (b) day treatment or other partial hospitalization services; and (c) psychiatric rehabilitation services. These services also may be offered in HCBS waiver programs serving other target populations that include individuals who have a "dual diagnosis" (e.g., mental retardation and a psychiatric condition). Clinic and day treatment services are primarily for diagnosis and treatment of mental illness. In contrast, psychiatric rehabilitation services are aimed primarily at achieving maximum reduction of physical or mental disability and restoration of maximum functioning.

The standard HCFA definitions of these services encompass a wide range of assistance to individuals who have a mental illness and are in keeping with contemporary views on mental health services. These views stress the need not only to treat the mental illness but also to assist individuals to function in their communities.

Clinic services: Outpatient mental health therapy and treatment.

States that select this option may offer mental health clinic services to HCBS waiver participants. The advantage of covering these services under an HCBS waiver program is that they may be furnished in locations other than clinic sites.[31]

Day treatment or other partial hospitalization services: Services necessary for diagnosis or treatment of an individual's mental illness. These services can include diagnostic services, psychotherapy, family counseling, occupational and activity therapy, medications, and training and education of the individual.

Day treatment services are akin to outpatient mental health services. Their purpose is to maintain the individual's condition and functional level and to prevent relapse or hospitalization. Partial hospitalization services are very similar to a hospital inpatient program, except the individual does not stay in the hospital 24 hours a day. With respect to adult services, day treatment is a term sometimes used interchangeably with partial hospitalization. But for children, it often means a facility-based day program that includes schooling, with supplemental mental health rehabilitation and / or counseling as well. The scope of services a state may furnish under an HCBS waiver

program is relatively broad. And unlike the Medicaid state plan clinic option, these services are not restricted to particular sites.

> *Psychiatric rehabilitation services: Medical or remedial services for maximum reduction of physical or mental disability and restoration of maximum functioning. Specific services include (a) restoration and maintenance of daily living skills (grooming, personal hygiene, cooking, nutrition, health and mental health education, medication management, money management, and maintenance of the living environment), (b) social skills training in appropriate use of community services, (c) development of appropriate personal support networks, (d) therapeutic recreational services (focused on therapeutic intervention rather than diversion[32]), and (e) telephone monitoring and counseling services.*

Psychiatric rehabilitation services integrate the provision of clinical mental health services with provision of other supports to address the full range of needs an individual with a mental illness might have. Day treatment services, in contrast, are confined largely to clinical services.

Health-related services

This category covers a variety of skilled services that persons with disabilities or chronic conditions may need but that either cannot be provided, or are provided on a more limited basis, under the state plan.

> *Skilled nursing: Services within the scope of a state's Nurse Practice Act that are provided by a registered professional nurse, or by a licensed practical or vocational nurse under the supervision of a registered nurse.*

This option enables a state to cover nursing services not available through the Medicaid state plan. Frequently, it is used in states where the Nurse Practice Act dictates that nurses perform various services on behalf of consumers (administer medications and injections, change feeding tubes, and so forth).

> *Private duty nursing: Individual and continuous care (in contrast to part-time or intermittent care) provided by licensed nurses within the scope of state law.*

Private duty nursing is similar to skilled nursing except that it is more intensive and can cover situations when a nurse must be with the person for extended periods throughout the day—including 24-hour-a-day coverage if needed to attend to the person's health care needs.

> *Extended state plan services: States may provide the same health and other services as available through the state plan, without the limitations on amount, duration, and scope specified in the plan. These services will be provided under the state plan until the plan limitations have been reached. They can include physician services; home health nursing services; physical and occupational therapy services; speech, language, and hearing services; prescribed drugs; dental services; vision services; and other state plan services.*

A state might choose to include these services in its HCBS waiver program because its state plan limits either the amount or scope of the services. (A) A state might limit the number of times an individual can receive physical therapy services, for example. By covering physical therapy as an "extended state plan" service, a state could provide for additional visits. (B) Or a state may require that physical and occupational therapy be provided only on a restorative basis (e.g., to individuals who have lost function as the result of an illness or accident). These therapies can also be valuable for individuals with permanent disabilities, however, because they can prevent deterioration and improve functioning.[33] An HCBS waiver program can include such coverage.[34]

Assistive devices, adaptive aids, and equipment; home and vehicle modifications

> *Environmental accessibility adaptations: Those physical adaptations to the home that either (a) are necessary to ensure the health, welfare, and safety of individuals or (b) enable them to function more independently in the home and without which they would require institutionalization.*

Home adaptations can almost never be covered under the Medicaid state plan. But Medicaid permits a wide range of adaptations under an approved waiver program.

Home and Vehicle Adaptations Included in Pennsylvania's HCBS Waiver Program

HCFA recently approved Pennsylvania's waiver program for individuals with mental retardation and related conditions. It includes the following household adaptations:

- Ramps from street, sidewalk, or house, including portable vehicle ramps
- Handrails and grab bars in and around the house
- That part of a smoke/fire alarm or detection system adapted for individuals with sensory impairments
- Outside railing from street to home
- Widened doorways, landings, and hallways
- Kitchen counter, major appliance, sink, and cabinet modifications
- Bathroom modifications for bathing, showering, toileting, and personal care needs
- Bedroom modifications of bed, wardrobe, desks, shelving, and dressers
- Workroom modifications to desks and other working areas
- Stair glider and elevating systems.

The waiver program limits physical adaptations to household vehicles to the following:

- Vehicular lifts
- Interior alteration such as seats, head and leg rests, and belts
- Customized devices necessary for the individual to be transported safely in the community, including driver control devices.

The various adaptations covered in Pennsylvania's HCBS waiver program are relevant to meeting the needs of individuals who have physical impairments regardless of the cause of their disability. In one form or another, coverage of these adaptations is very common in HCBS waiver programs that serve individuals with physical impairments, regardless of their age or specific condition.

Specialized medical equipment and supplies: Devices, controls, or appliances that enable individuals to increase their abilities to perform ADLs, or to perceive, control, or communicate with the environment in which they live. This service also includes items necessary for life support, ancillary supplies, and equipment necessary to the proper functioning of such items, and durable and nondurable medical equipment not available under the Medicaid state plan.

This coverage can address a variety of needs and purposes. These include providing:

- Aids and devices to enable persons with memory impairments to adhere to a medication schedule (e.g., medication administration boxes with timed alarms)

- Communication aids and devices, including expressive and receptive communication augmentative devices (e.g., electronic communication devices)

- Skill acquisition supports that make learning more purposeful and useful, including computers, computer adaptations, software, or instructional aids

- "Assistive technology" services. These cover a full range of services and adaptations that enable individuals with severe disabilities to use technology to perform activities on their own.

An enormous variety of devices and supplies can be offered under this coverage. Again, it is more common than not for HCBS waiver programs that serve persons with physical impairments to cover these services. One of the main benefits of covering many of these services is that they can reduce the need to provide workers to perform tasks on behalf of individuals, enabling them to be more independent and self-sufficient.

In addition to equipment and devices, states may cover other types of services in order to provide assistance in a different form. California's developmental disabilities waiver program, for exam-

ple, covers "communication aides," which are "those human services necessary to facilitate and assist persons with a hearing, speech, or vision impairment to be able to effectively communicate with service providers, family, friends, co-workers, and the general public." Allowable communication aides include (a) facilitators; (b) interpreters and interpreter services; (c) translators and translator services; and (d) readers and reading services.

> *Personal emergency response systems or PERS: Electronic devices that enable certain individuals at high risk of institutionalization to secure help in an emergency. PERS services are limited to those individuals who live alone, who are alone for significant parts of the day, or who have no regular caregiver for extended periods of time, and would otherwise require extensive routine supervision.*

These systems are covered in HCBS waiver programs that serve a variety of populations, particularly elderly persons. Equipping consumers with this capacity reduces the need for on-site oversight and makes it possible for individuals to live more independently and safely. Some states have defined PERS more broadly than the standard definition. California's HCBS waiver program for people with developmental disabilities, for example, covers the following items as PERS: (a) 24-hour answering/paging; (b) beepers; (c) MedicAlert bracelets; (d) intercoms; (e) life-lines; (f) fire/safety devices, such as fire extinguishers and rope ladders; (g) monitoring services; (h) light fixture adaptations (blinking lights, etc.); (i) telephone adaptive devices not available from the telephone company; and (j) other electronic devices/services designed for emergency assistance.

> *Transportation: Services that enable waiver participants to gain access to waiver and other community services, activities, and resources specified by the plan of care. This service must be a supplement to mandatory assurance of medical transportation,[35] and to other transportation services that may be provided under the state plan.*[36]

Coverage of transportation services can be complicated because of the need for coordination with "medical transportation" as available under the state Medicaid plan. General "medical transportation" must be used when the person needs to obtain a health care service (e.g., go to the doctor). Transportation services under an HCBS waiver program, sometimes called "non-medical transportation," can be used to pay for transporting individuals either to sites where home and community services are provided (e.g., an adult day health program) or to reach other community services (which must be reflected in the person's plan of care).

HCBS waiver transportation services can take a variety of forms—including reimbursing mileage expenses of a family member or a friend, if necessary to provide the transportation.

Family training and respite care

These services are provided to help family members in, and relieve them of, their caregiving responsibilities.

> *Family training: Training and counseling services for the families of individuals served under an HCBS waiver. Includes instruction about treatment regimens and use of equipment specified in the plan of care.*

> *Respite care: Services provided to individuals unable to care for themselves, furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care.*

These services are discussed in detail in Chapter 8.

Additional Waiver Services That Have Been Approved by HCFA

Even though HCFA has expanded the number of services contained in its standardized format since it was first issued, the current list by no means exhausts all coverage possibilities and variations thereof. For example, waiver programs for older persons can cover home-delivered meals and protective services. Waiver programs for persons with acquired brain disorders can include family counseling to deal with behavioral and other problems and substance abuse counseling/services. Colorado covers training in child and infant care for a parent with a disability.

Mobile Crisis Intervention: A Waiver Service in California

California's developmental disabilities waiver program covers a service called "mobile crisis intervention." This is defined as immediate, time-limited, therapeutic intervention on a 24-hour emergency basis to an individual exhibiting acute personal, social, and/or behavioral problems which, if not addressed, are likely to escalate into situations which would threaten the health and safety of the individual and result in the individual being removed from the current living arrangement.

The following is an illustrative list of services states have included in their waiver programs that serve individuals with developmental disabilities. Many of these services are applicable to other disability groups and can be modified to address the unique needs of each target population.

Crisis intervention services. These services usually entail providing additional, frequently specialized, services to HCBS waiver beneficiaries who are in crisis, usually due to a behavioral problem or episode. The services typically enable specialists to be dispatched to stabilize the persons in their current living arrangement. Without such services, persons with developmental disabilities may face transfer from their current living situation to institutional settings because they, their parents, or their service providers are unable to respond appropriately to transitory crisis situations. Professional intervention has been demonstrated to be effective in resolving such crises and precluding or reducing their recurrence—thus preventing reinstitutionalization—through training of the individual or relevant others in how to manage the behaviors that precipitate the crisis situations.

Behavioral services. More generally, states often cover behavioral services in HCBS waiver programs for people with developmental disabilities and persons with acquired brain injuries. Provision of such services provides a means to secure specialists to address behavioral problems or issues on a continuing basis.

Community participation supports. Some waiver programs have distinct coverages that assist individuals to participate in community activities away from formal program sites. The aim is to encourage greater community integration and reduce use of site-based programs. For example, Colorado includes in the scope of the personal assistance services offered through its HCBS waiver program "mentorship activities, such as assistance with his/her participation on private and public boards, advisory groups, and commissions."

Housing coordination. Housing coordination involves providing an individual with assistance in locating community housing, including helping the individual gain access to various types of housing assistance. A few states have added this coverage to their HCBS waiver programs.

Supported living. Supported living involves bringing needed services and supports to individuals in housing they own or lease. Many states have launched supported living programs for people with developmental disabilities. They have done so in order to foster independence and community integration, as well as reduce the extent to which individuals who do not live with their families must rely on provider agencies for housing. Including supported living in an HCBS waiver program enables a state to tie together several types of services and supports into a single coverage—in much the same fashion as the "residential habilitation" coverage does for provider-operated living arrangements.

Many states have linked their coverage of supported living to making non-Medicaid supplementary funding available to assist individuals in meeting the expenses associated with setting up their own living arrangement (e.g., making deposits and acquiring furniture), or with rent when their own income and resources are not sufficient due to particularly high housing costs. Connecticut has set aside funds expressly for these purposes. Florida has a similar program.

Consumer training and education. Recently, some states have added coverage of consumer education and training aimed explicitly at teaching individuals skills they need to manage their own supports and advocate on their own behalf.

California's Definition of Supported Living in Its HCBS Waiver Program for People with Developmental Disabilities

Supported living services in California include any individually designed service, or assessment of the need for service, which assists an individual consumer to live in a home that they own or lease, which is not licensed, and which is not the place of residence of a parent or conservator, with support available as often and for as long as it is needed.

The purposes of supported living services include assisting the consumer to make fundamental life decisions, while also supporting and facilitating the consumer in dealing with the consequences of those decisions; building critical and durable relationships with other individuals; choosing where and with whom to live; and controlling the character and appearance of the environment within their home. Supported living services are tailored to meet the individual's evolving needs and preferences for support without having to move from the home of their choice.

Examples of supported living services activities include assistance with common daily living activities; meal preparation, including planning, shopping, cooking, and storage activities; routine household activities aimed at maintaining a clean and safe home; locating and scheduling appropriate medical services; acquiring, using, and caring for canine and other animal companions specifically trained to provide assistance; selecting and moving into a home; locating and choosing suitable housemates; acquiring household furnishings; settling disputes with landlords; becoming aware of and effectively using the transportation, police, fire, and emergency help available in the community to the general public; managing personal financial affairs; recruiting, screening, hiring, training, supervising, and dismissing personal attendants; dealing with and responding appropriately to governmental agencies and personnel; asserting civil and statutory rights through self-advocacy; building and maintaining interpersonal relationships, including a "circle of support"; participating in community life; and accessing emergency assistance (including selection, installation, maintenance, repair, and training in the operation of devices to facilitate immediate assistance in the face of threats to health, safety, and well-being).

* * *

The foregoing makes it clear that no exact recipe exists for deciding which services and supports to include in a particular HCBS waiver program. As some wit has put it: "What HCBS waiver programs have most in common is that they are all different."

Why are they so different? After all, states typically have a great deal in common in the groups of individuals with disabilities or chronic conditions that they wish to serve. There are several reasons for the differences, of varying importance.

Some of the large differences among HCBS waiver programs that serve similar target populations are less significant than meet the eye. Some states, for example, elect to break down their services into many distinct coverages, whereas others pull together various closely related services into one coverage category. One of Colorado's HCBS waiver programs for people with developmental disabilities, for example, covers a service it has named "rehabilitation engineering." Under this coverage, it offers services other states choose to break down into home modifications, assistive technology, adaptive aids, and so forth. How exactly services and supports are packaged is less important than making sure they are covered in one fashion or another. Again, the best starting point for designing and selecting HCBS waiver coverages is assessing the needs of the service population and developing a state's own concrete ideas about how those needs can best be met.

A more substantive reason why state HCBS waiver services vary so widely is differences among states in the services already covered under the state Medicaid plan. In states that have broad, comprehensive state plan coverages, the services a state offers under its HCBS waiver program will consist mainly of those that cannot otherwise be covered under the state plan. This explains why,

for example, some states cover therapeutic services under their waiver programs and others do not. It also explains why HCBS waiver programs that principally serve children usually offer fewer services than programs that principally serve adults with disabilities. Since Federal law mandates that states provide the full array of state plan services to children, whether or not they are covered under a state's plan, HCBS waiver programs for children furnish a more limited array of additional services.

Differences among target populations are also important. As discussed earlier, several types of HCBS waiver services cut across disability lines (e.g., personal care/personal assistance, service coordination, and home modifications). These—and other services—are needed by people with different types of disabilities and are covered in nearly all HCBS waiver programs. However, there are also differences among individuals that are linked to their disabilities and how those disabilities need to be addressed. For example, habilitation training is particularly important for people with developmental disabilities, such as mental retardation and acquired brain injury, because of the nature of their disability.[37] (Indeed, provision of habilitation usually accounts for a significant share of the expenditures in HCBS waiver programs that serve people with developmental disabilities and is one reason why these waiver programs tend to be relatively costly to operate.) However, habilitation training is not relevant in meeting the needs of most elderly individuals. Thus, state coverage decisions are very much tied to the specific needs of individuals in the target population.

Yet another substantive reason why states differ in the services and supports they offer through their HCBS waiver programs is that home and community services and supports are still developing. Approaches that seemed appropriate in the past give way to new approaches. And states vary in how quickly they embrace these changes. One of the best features of the HCBS waiver alternative is that it is sufficiently flexible to change with the times. Waiver programs that have been in operation for a relatively long period, for example, usually have changed considerably since they were first approved.

A key point to keep in mind is that states have considerable latitude to modify and even change their HCBS waiver coverages. Each year, states submit a high volume of amendments to their HCBS waiver programs which add, delete, and modify the services and supports states offer. As a consequence, each HCBS waiver program typically is a "work in progress." Coverages can be fine-tuned based on feedback from people with disabilities and service providers concerning problems or gaps. In this context, hindsight can be a powerful strategic planning tool.

Endnotes

1. The primary contributors to this chapter are Gary Smith and Janet O'Keeffe.

2. Sections 1902(a)(10)(B) and 1902(a)(1) of the Social Security Act.

3. Section 1915(c) of the Social Security Act. The relevant Federal statute authorizes the Secretary of HHS to grant these waivers.

4. It is increasingly common, for example, for states to offer, under HCBS waiver programs for people with developmental disabilities, supplementary dental services over and above the dental benefits available under the state plan, which are typically very limited. This "extended" coverage option can be and is employed for other Medicaid state plan services as well (physician services, prescribed drugs, vision services).

5. Section 1915(c)(1) of the Social Security Act prohibits payment for room and board under Medicaid waivers.

6. These services are listed in Section 1905(a) of the Social Security Act.

7. Adding or changing coverage of home and community services that Federal law permits to be covered under the Medicaid state plan requires a state to take various formal steps. A state adds, deletes, or changes a service in its Medicaid state plan by filing a state plan amendment with HCFA, which reviews the coverage and approves it so long as it conforms to Federal law and Federal regulations.

8. The 1997 regulations can be found at 42 CFR 440.167.

9. In the developmental disabilities service field, when people with cognitive impairments and severe disabilities are not able to direct all aspects of their services, other consumer-directed approaches have been employed. For example, "circles of support" are com-

posed of individuals' family and friends, who work in concert to provide assistance to help them realize their goals.

10. U.S. General Accounting Office. (May 1999) *Adults with severe disabilities: Federal and state approaches for personal care and other services*. GAO Publication No. GAO/HEHS-99-101. Washington, DC: GAO.

11. Among the states that offered personal care services in 1998, annual per capita outlays for such services (i.e., total personal care expenditures divided by the state's total population) ranged from less than $0.10 to a high of $94.37. Burwell, B. (April 25, 2000). Memorandum: Medicaid long-term care expenditures in FY 1999. Cambridge: The MEDSTAT Group. (A few of the states included in the MEDSTAT data analysis cover personal care services only for children covered by the EPSDT mandate, which likely accounts for the very low amount spent in some states.)

12. The limits each state imposes are listed in U.S. General Accounting Office. (May 1999) *Adults with severe disabilities: Federal and state approaches for personal care and other services*. GAO Publication No. GAO/HEHS-99-101. Washington, DC: GAO.

13. For three of these states (AR, OK, WA), limiting personal care services to the categorically needy is a departure from policies on other benefits in their Medicaid programs, which are offered to both categorically eligible and medically needy individuals. Ibid.

14. This state option was added in Section 1915(g) of the Social Security Act.

15. HCFA guidelines concerning targeted case management services are in Sections 4302 *et seq.* of the State Medicaid Manual.

16. Activities related to eligibility determinations and service authorization may be reimbursed as administrative expenses.

17. States are required to ensure that appropriate transportation is available. See the transportation provisions in 42 CFR 431.53. Transportation may also be provided as a service under the state plan.

18. Defined in 42 CFR 440.90 with additional HCFA guidelines in Section 4320 of the State Medicaid Manual.

19. Defined in 42 CFR 440.130(d).

20. Teaching parents to anticipate and deal with a child's rage is an example of an activity that directly supports the Medicaid beneficiary. Marriage counseling for the child's parents does not and is not covered.

21. Much of the information provided here on the rehabilitation service option is drawn from Koyanagi, C. and Brodie, J. (July 1994). *Making Medicaid work to fund intensive community services for children with serious emotional disturbances.* Washington, DC: Bazelon Center for Mental Health Law. This publication is no longer available because it has been updated and published in two new companion reports. See the annotated bibliography at the end of this chapter for a description of these excellent publications.

22. Statutory authority for HCBS waiver programs is contained in Section 1915(c) of the Social Security Act. Applicable Federal regulations are found at 42 CFR 441 Subpart G. These regulations were last modified in 1994. HCFA guidelines concerning HCBS waiver programs are contained in Sections 4440 *et seq.* of the State Medicaid Manual. These guidelines are updated periodically.

23. With respect to services a state proposes to cover that depart from those that appear in the standard application format, HCFA requires that "the definition of each service must be exhaustive (e.g., a detailed list of each item of medical equipment that may be provided) or closed-ended (e.g., "only those medical supplies needed for the respirator-related needs of a respirator-dependent patient"). The definition may not include such phrases as "including but not limited to . . .," "for example . . .," "including . . .," "etc." In other words, the service must be defined in a fashion that makes clear exactly what will be furnished to the beneficiary.

24. When case management services are furnished under an HCBS waiver program, individuals have the right to select their case managers from among all qualified providers of such services.

25. The term "habilitation" is defined in the standard application as "services designed to assist individuals in acquiring, retaining and improving functioning." It is distinguished from "rehabilitation," which involves the *restoration* of function. Habilitation services have generally been provided to individuals who have cognitive impairments, including those due to mental retardation, brain trauma, or acquired brain disorders. However, habilitation services can be provided to anyone who can benefit from them, regardless of age or diagnosis.

26. Adult foster care services are also provided under the rehabilitation option as therapeutic foster care.

27. Both the states and various Federal agencies have emphasized the need to assist people with developmental disabilities to obtain employment in regular jobs in the community. In 1986 Congress permitted states to offer extended habilitation services through HCBS waiver programs, but restricted those services to

individuals who had been institutionalized some time prior to entering the HCBS waiver program. In spite of this restriction, nearly all states that operate HCBS waiver programs for people with developmental disabilities have added some of these services—particularly supported employment—to their programs. However, only a small portion of HCBS waiver participants with developmental disabilities have been provided this service, due in large part to the prior institutionalization test.

Congress agreed to remove this test as a provision of the Balanced Budget Act of 1997. This step prompted some states that had not previously covered supported employment services to add them to their waiver programs. By early 1999, most states had changed their coverage of supported employment services to broaden their availability to all HCBS waiver participants. In a recent letter to State Medicaid Directors, HCFA clarified that these services can be offered to all waiver participants who can benefit from them, not just to persons with mental retardation or other developmental disabilities.

28. This prohibition on reimbursement is in line with the Federal requirement that Medicaid be the payer of last resort when other public programs cover the same service.

29. However, individuals who receive prevocational services can be compensated for their work. In keeping with Federal hourly wage statutes, persons who are compensated at levels above 50 percent of the minimum wage are generally regarded as receiving vocational rather than prevocational services.

30. A state may furnish these services only in instances when similar services are not available through the state's vocational rehabilitation program (or in the case of older youth, special education programs).

31. States have the flexibility to define waiver services and provider requirements as long as they adhere to state mandates regarding licensure and certification and other applicable requirements.

32. Diversion as used here is defined as leisure activities without a treatment objective.

33. Another example is in the arena of prescribed drugs. The state plan might restrict the types of drugs that may be purchased. Sometimes individuals can benefit from medications not on the approved list and these can be secured as an "extended state plan" service. A few states have gone a step farther to cover nonprescription medications. Michigan's HCBS waiver program for people with developmental disabilities includes coverage of "extended pharmacy services," for example, which includes various over-the-counter items that are physician ordered.

34. When a state does not cover a health-related service under its state plan but desires to do so under its HCBS waiver program, the service is not considered an "extended state plan" coverage but a coverage in its own right. Services falling into this category can include (depending on what a state's basic Medicaid program offers) dietary services, special meals, respiratory therapy, psychology services, recreation therapy, and so forth.

35. Required under 42 CFR 431.53.

36. Defined at 42 CFR 440.170(a).

37. Persons of all ages with many different types of disabilities can benefit from habilitation services. Coverage of habilitation has generally been provided only to people with developmental disabilities, which are defined as those occurring before age 22. However, a recent HCFA letter to State Medicaid Directors clarifies that neither Medicaid law nor implementing regulations restrict who may receive habilitation services in an HCBS waiver. Individuals who do not have mental retardation or other developmental disabilities, such as persons with traumatic brain injury or physical disabilities that occurred after age 22, may also receive habilitation services through a waiver program. (See Appendix II for the complete text of HCFA's guidance.)

Annotated Bibliography

LeBlanc, A.J., Tonner, M.C., and Harrington, C. (2000). ***State Medicaid programs offering personal care services.*** **San Francisco: University of California.** (40 pages)

This paper describes the two predominant means through which Americans with disabilities receive personal care services: the Medicaid personal care service optional state plan benefit and the Medicaid 1915(c) home and community based services waiver program. It presents state and national data on the number of Medicaid personal care participants and program expenditures. It also describes how the states vary in their implementation of the two programs. *The paper may be ordered for $5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

LeBlanc, A.J., Tonner, M.C., and Harrington, C. (2000). ***Medicaid 1915(c) home and community based services waivers across the states: Program structure and barriers to growth.*** **San Francisco: University of**

California. (33 pages)

This paper describes the program structure, policies, and administration of Medicaid 1915(c) home and community based services waiver programs. The paper also describes how states incorporate the waiver programs into their larger long-term care administrative structure. The authors also identify structural barriers to waiver program growth, including dispersed administrative structures, limits on financial eligibility, cost caps, and formal limits on service use. *The document may be ordered for $5.00 by e-mail at sbs@itsa.ucsf.edu or by calling (415) 476-3964.*

Koyanagi, C. (September 1999). ***Making sense of Medicaid for children with serious emotional disturbance. A review of how states provide access to the most effective community based services for children on Medicaid who need mental health care.*** **Washington, DC: Bazelon Center for Mental Health Law.** (90 pages)

This publication surveys 68 state programs and summarizes innovative approaches in several states using Medicaid under managed care and fee-for-service to finance wraparound services. *This report (CM-1) may be ordered for $18.90 from the Bazelon Center for Mental Health at www.bazelon.org; or send e-mail to pubs@bazelon.org or call (202) 467-5730 extension 41, or write to Bazelon Center for Mental Health, 1101 15th Street, N.W., Suite 1212, Washington, DC 20005-5002, or fax request to (202) 223-0409.*

Koyanagi, C. (September 1999). ***Where to turn: Confusion in Medicaid policies on screening children for mental health needs. A report on states' use of EPSDT to identify children who need mental health services.*** **Washington, DC: Bazelon Center for Mental Health Law.** (18 pages)

This publication discusses how states are currently failing to use Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program (EPSDT) to identify children who need mental health services. It includes a state-by-state comparison chart of EPSDT screening requirements and recommendations for advocates, policymakers, and program administrators. *This report (CM-2) may be ordered for $12.90 from the Bazelon Center for Mental Health at www.bazelon.org; or send e-mail to pubs@bazelon.org or call (202) 467-5730 extension 41, or write to Bazelon Center for Mental Health, 1101 15th Street, N.W., Suite 1212, Washington, DC 20005-5002, or fax request to (202) 223-0409. Special price for both publications (CM-3): $27. See on-line bookstore or e-mail pubs@bazelon.org for bulk discounts.*

U.S. General Accounting Office (May 1999). ***Adults with severe disabilities: Federal and state approaches for personal care and other services.*** **GAO Publication No. GAO/HEHS-99-101. Washington, DC: Author.** (86 pages)

This report provides an overview of how adults with disabilities received home and community based services under Medicaid in 1994. Data are derived from the 1994–1995 National Health Interview Survey. It also includes interviews with disability-related advocacy and research groups, a list of state programs that meet the needs of adults with severe disabilities, and a profile of four innovative personal care programs in California, Kansas, Maine, and Oregon. *This document can be downloaded free of charge from the Internet at frwebgate.access.gpo.gov or by calling the GAO Document Distribution Facility at (202) 512-6000, or by writing to 441 G Street, N.W., Room 6252, Washington, DC 20548.*

U.S. General Accounting Office (April 1999). ***Assisted living: Quality of care and consumer protection issues in four states.*** **GAO Publication No. GAO/HEHS-99-27. Washington, DC: Author.** (55 pages)

Although most assisted living costs are paid for privately by individuals, several state Medicaid programs fund services for residents in assisted living facilities and many other states have expressed interest in doing so. This study explores quality of care and consumer protection issues surrounding assisted living programs in California, Florida, Ohio, and Oregon (states chosen for their experience with assisted living programs). *This document can be downloaded free of charge from the Internet at frwebgate.access.gpo.gov or by calling the GAO Document Distribution Facility at (202) 512-6000, or by writing to 441 G Street, N.W., Room 6252, Washington, DC 20548.*

Mollica, R.L. (June 1998). ***State assisted living policy: 1998.*** **Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy.** (295 pages)

This study identifies trends in the demand for and supply of assisted living facilities; barriers to the development of assisted living; and supply/demand factors that contribute to those barriers. It evaluates the concept of "assisted living," and describes the key characteristics of the universe of assisted living facilities. The study reviews assisted living and board and care policies in the 50 states and describes the primary approaches that states are taking to license assisted liv-

ing. Medicaid reimbursement policy for assisted living is also discussed. Summaries of each state's policy and regulations covering assisted living and board and care are presented. The study is an excellent resource / reference guide. *To obtain a free copy of this report, write to the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201, fax (202) 401-7733, or e-mail DALTCP2@osaspe.dhhs.gov.*

Schore, J., Harrington, M., and Crystal, S. (March 1998). ***The role of home and community based services in meeting the health care needs of people with AIDS.*** **Final report. Princeton, NJ: Mathematica Policy Research.** (149 pages)

This report reviews the recent literature describing the delivery and financing of home and community based services for people with AIDS, case studies of service provision in New York City and Los Angeles, and an analysis of use and reimbursement patterns for New Jersey Medicaid beneficiaries with AIDS. The case studies describe current provider approaches to delivering home and community based services to the AIDS population. A synthesis of information (i.e., evolution of improvements in AIDS treatment, changes in the AIDS population, and pressures to control spending) and their implications are addressed. *The report may be ordered for $12.00, plus shipping and handling, from Jackie Allen, librarian, Mathematica Policy Research, Inc., PO Box 2393, Princeton, NJ 08543-2393, (609) 275-2350, or e-mail jallen@mathematica-mpr.com.*

Schore, J., Harrington, M., and Crystal, S. (1998). ***Serving a changing population: Home and community based services for people with AIDS.*** **Pub. #PR98-15. Princeton, NJ: Mathematica Policy Research, Inc.** (10 pages)

This study examines the availability of and funding for home and community based services for people with AIDS. It includes a literature review, case studies, and an analysis of use and reimbursement patterns for New Jersey Medicaid beneficiaries with AIDS. It compares home care use and costs for Medicaid beneficiaries with AIDS in New Jersey's AIDS waiver program with those not served by a waiver. The study analyzes the challenges facing providers, planners and policymakers with regard to information needs, an integrated approach under managed care, and the needs of people with chronic illness. *This report may be ordered free of charge from Jackie Allen, librarian, Mathematica Policy Research, Inc., PO Box 2393, Princeton, NJ 08543-2393, (609) 275-2350, or e-mail jallen@mathematica-mpr.com.*

Schoff, J., and Schore, J. (January 1997). ***The role of home and community based services in meeting the health care needs of people with AIDS.*** **Literature review. Princeton, NJ: Mathematica Policy Research.** (92 pages)

This report reviews the literature published between 1993 and 1998 on the delivery and financing of home and community based services for people with AIDS. It describes gaps in information, services that are available (including program descriptions), funding sources, and managed care. Detailed program descriptions provide models that can be used to design AIDS programs. *The report may be ordered for $12.00, plus shipping and handling, from Jackie Allen, librarian, Mathematica Policy Research, Inc., PO Box 2393, Princeton, NJ 08543-2393, (609) 275-2350, or e-mail jallen@mathematica-mpr.com.*

Kassner, E., and Williams, L. (September 1997). ***Taking care of their own: State-funded home and community based care programs for older persons.*** **Washington, DC: AARP, Public Policy Institute.** (56 pages)

This document provides a summary and brief analysis of state-funded multi-service programs that provide home and community based services to older persons. The data are based on a 1996 survey undertaken by AARP and include a general description of existing types of programs as well as a more specific and descriptive chart on the different services offered in 49 states and the District of Columbia (Montana did not respond to the survey). The report is useful in conjunction with other studies that provide data on federally funded programs. *To obtain a free copy of this document, contact AARP's Public Policy Institute at (202) 434-3860 or search their website at http://www.research.aarp.org.*

Lewin-VHI, Inc. (1996) ***National study of assisted living for the frail elderly: Literature review update.*** **Washington, DC: Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.** (87 pages)

This document reviews published and unpublished literature on assisted living for the frail elderly from 1992 through September 1995. It synthesizes information gathered from 175 articles. It discusses current trends in assisted living and compares state policies and practices. *To obtain a free copy of this report, write to the Office of Disability, Aging, and Long-Term Care Policy, Room 424E, H.H. Humphrey Building, 200 Independence Avenue,*

S.W., Washington, DC 20201, fax (202) 401-7733, or e-mail DALTCP2@osaspe.dhhs.gov.

U.S. General Accounting Office (1994). *Medicaid long-term care: Successful state efforts to expand home services while limiting costs*. GAO Publication No. GAO/HEHS-94-167. Washington, DC: Author. (50 pages)

This document provides a review of three states' (Oregon, Washington, and Wisconsin) experience in expanding government-funded home and community based services. It focuses on these states' experience in shifting the provision of long-term care from institutional to home and community based settings. This document explains mechanisms states have used to control costs. It also demonstrates how the use of home and community based care has enabled states to provide services to a greater number of people. Detailed descriptions of each state and relevant data enhance understanding of how to design and manage a successful program. *This document can be downloaded free of charge from the Internet at frwebgate.access.gpo.gov or obtained by calling the GAO Document Distribution Facility at (202) 512-6000, or by writing to 441 G Street, N.W., Room 6252, Washington, DC 20548.*

Leonard, B., Brust, J., and Choi, T. (1989). Providing access to home care for disabled children: Minnesota's Medicaid waiver program. *Public Health Report* 104: 465–72. (7 pages)

This article explores the availability of funding for home care under the Minnesota Medicaid waiver program. It discusses gaps in funding for home care as well

as barriers to coverage (i.e., complex applications and poorly coordinated systems of care). It also provides a brief history of services for technology-dependent children and a history of Minnesota's program and eligibility criteria. The article reviews 96 records in the Minnesota home and community based model waiver program and follows their outcomes (e.g., approval/denial of application, coordination of care between state agencies). The article includes recommendations to help states remove the obstacles consumers face when seeking home and community based services.